



Rare 2030 Panel of Experts

Membership List for Sub-Group 4: Basic, Clinical, Translational and Social Research*

Surname	First Name	Type of Stakeholder**	Country
Agius	Francis	National/Regional Competent Authority (National policy maker)	MT
Alves	Inês	Patient advocate	PT
Amin	Ahmad	ERN Coordinator/ERN Healthcare Provider representative	NL
Ardigò	Diego	Pharmaceutical Industry and other health-related industries	IT
Balfour	Jo	Patient advocate	UK
Blay	Jean-Yves	ERN Hospital Manager	FR
Brambilla	Isabella	Patient advocate	IT
Bros-Facer	Virginie	European research networks and infrastructures	FR
Buske	Orion	Individual Researcher	CA
Dallapiccola	Bruno	National/Regional Competent Authority (National policy maker)	IT
Driessens	Mariette	Regulatory expert	NL
Eichler	Hans-Georg	Regulatory Expert	NL
Feitz	Wout	ERN Coordinator/ERN Healthcare Provider representative	NL
Fonseca	Valter	National/Regional Competent Authority (National policy maker)	PT
Galetti	Ilaria	Patient advocate	IT
Goodhand	Peter	International Initiatives	CA
Grentoft	Mette	Patient advocate	DK
Guillén-Navarro	Encarna	Social care and social innovation experts	ES
Guillot	Florence	International Initiatives	FR

Incerti	Carlo	Pharmaceutical Industry and other health-related industries	NL
Julkowska	Daria	European research networks and infrastructures	FR
Kaariainen	Helena	National/Regional Competent Authority (National policy maker)	FI
Kotulska-Jozwiak	Katarzyna	National/Regional Competent Authority (National policy maker)	PL
Lohse	Ansgar	ERN Coordinator/ERN Healthcare Provider representative	DE
Lopez Granados	Eduardo	ERN Coordinator/ERN Healthcare Provider representative	ES
Magenheim	Rita	Patient Advocate	NL
Mann	Mirjam	Patient advocate	DE
Martin	Simona	EU policy makers	IT
McKay	Lucy	Individual Researcher	UK
Moll	Nathalie	Pharmaceutical Industry and other health-related industries	BE
Muthyala	Ramaiah	International initiatives	US
O'Connor	Dan	Regulatory expert	UK
Özbek	Uğur	Individual Researcher	TR
Palau	Francesc	Individual experts involved in the European Joint Actions for Rare Diseases	ES
Palma	Ana	Pharmaceutical Industry and other health-related industries	BE
Parker	Samantha	Pharmaceutical Industry and other health-related industries	FR
Richards	Tessa	Journalist	UK
Sangiorgi	Luca	ERN Coordinator/ERN Healthcare Provider representative	IT
Scarpa	Maurizio	ERN Coordinator/ERN Healthcare Provider representative	IT
Schaefer	Franz	ERN Coordinator/ERN Healthcare Provider representative	DE
Schuster	Ralph	European research networks and infrastructures	DE
Scollen	Serena	European research networks and infrastructures	UK
Stoyanova-Beninska	Violeta	Regulatory expert	NL



Summar	Marshall	International initiatives	US
Tarauscio	Domenica	National/Regional Competent Authority (National policy maker)	IT
Trama	Annalisa	ERN Coordinator/ERN Healthcare Provider representative	IT
Tumiene	Birute	National/Regional Competent Authority (National policy maker)	LT
Ussi	Anton	European research networks and infrastructures	NL
van Doorne	Cathalijne	Patient advocate	BE
van Weely	Sonja	European research networks and infrastructures	NL
Ward	Adrian	Pharmaceutical Industry and other health-related industries	CH
Wijnen	Rene	ERN Coordinator/ERN Healthcare Provider representative	NL
Wulffraat	Nico	ERN Coordinator/ERN Healthcare Provider representative	NL
Zain	Rula	Individual Researcher	SE

(NB The following panel members were *assigned* to this group and may wish to change!)

Surname	First Name	Type of Stakeholder**	Country
Pereira	Alberto	ERN Coordinator/ERN Healthcare Provider representative	NL
Straus	Sabine	Regulatory expert	NL

*This sub-group includes issues such as research infrastructures; research programmes; innovation-centric health systems, patient-centred research, etc.

**Many people in this Panel of Experts belong to numerous categories – the ‘Type of Stakeholder’ listed against each name represents the *primary* capacity in which experts were invited to this Panel.